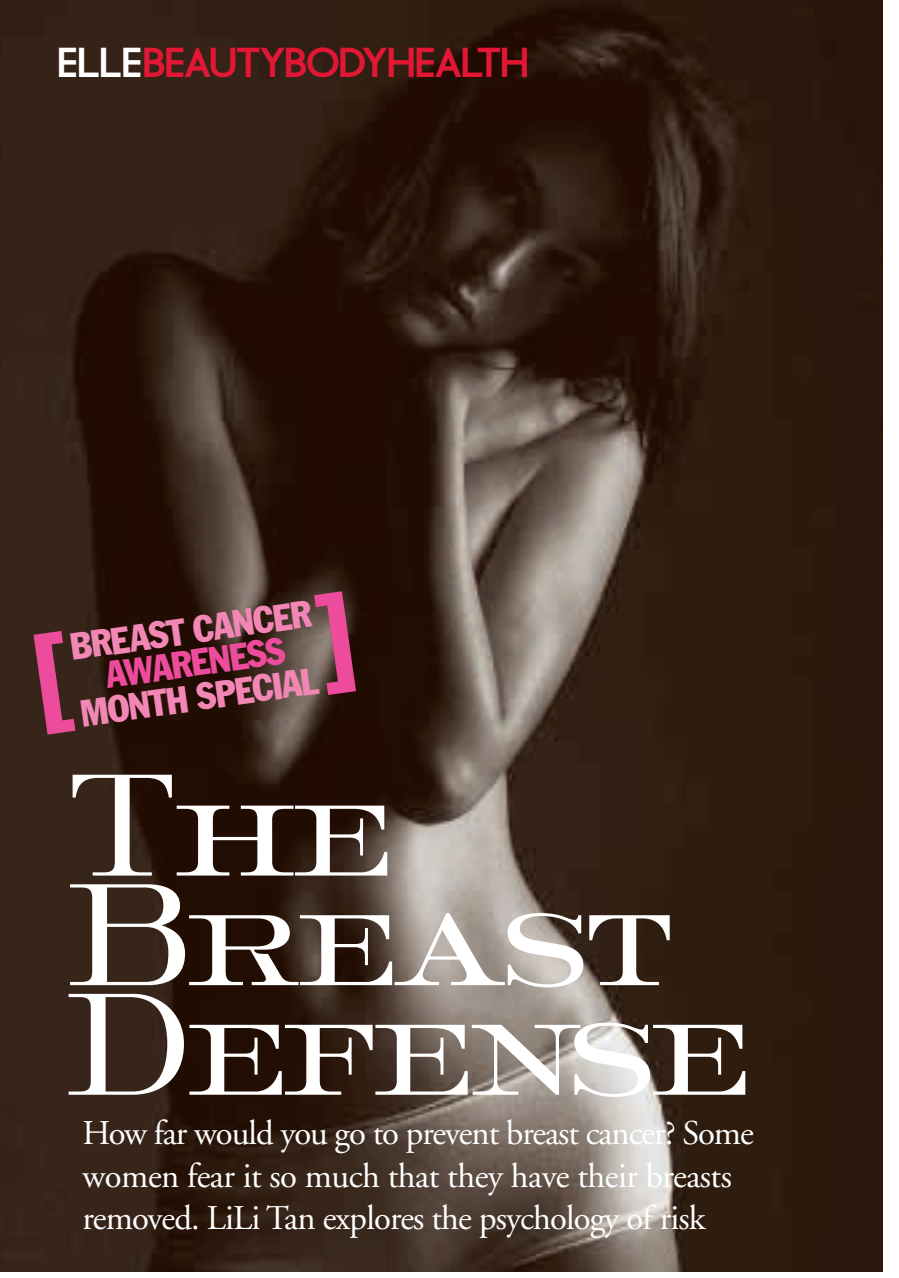

BREAST CANCER AWARENESS MONTH SPECIAL

The Breast Defense

How far would you go to prevent breast cancer? Some women fear it so much that they have their breasts removed. LiLi Tan explores the psychology of risk

The waiting room at Manhattan's Murray Hill Radiology and Mammography clinic isn't as packed as usual. On this morning in mid-July, Lisa, a 46-year-old nurse who's considering surgically removing her breasts to prevent breast cancer, is lucky enough to have a chair. She's waiting to see her radiologist about a lump she's found in her left breast, which has grown noticeably larger than the right and has been secreting discharge from the nipple since winter. This could lead to her second biopsy in one year. "I feel like this [visit] has already put me over the edge…not knowing," says Lisa—whose two grandmothers and two aunts have had breast cancer, and who has two cousins presently battling the disease. "I am so afraid of losing my breasts. But I'm also terrified of keeping them."

Mal [not her real name], a 46-year-old married mother of two, faced a similar conundrum nearly two years ago before deciding to have her breasts removed in a procedure known as bilateral prophylactic mastectomy (BPM). It was an attempt to avoid the disease her mother had suffered through at 47. "I remember thinking, 'My mother's going to die,'" Mal says, recalling her mother lying in a hospital bed connected to Hemovac drains after the four operations it took to remove both breasts. (She ultimately survived.) "She was totally carved. Butchered."

Mal's chances of getting breast cancer were high, 40 to 50 percent over her lifetime, due to her family history. Over several years, her doctors had biopsied a number of noncancerous lesions; then, a year and a half ago, Mal was diagnosed with lobular carcinoma in situ (LCIS) and atypical ductal hyperplasia (ADH), two conditions that can indicate an elevated risk of developing the disease. One year after her BPM with reconstruction, Mal is confident she made the right decision. "I lost my risk—that's all," she says. "[My breasts] weren't [a part of] my identity—I'm not living in fear anymore."

Removing one's breasts without a cancer diagnosis may seem extreme. Technically it is: The surgery can be physically and emotionally traumatic and, as with any invasive procedure, subject to complications. But compared with other prophylactic measures, including estrogen-receptor modulating drugs such as tamoxifen, it also offers the best insurance against developing the disease, a 90 percent cut in risk. (It's possible, though rare, for cancer to develop in tissue that remains in the chest wall.) For some women who are gripped by fear over their genetic destiny, a BPM represents the only option. Inevitably, their choice can be a controversial one.

"Part of what may be driving the women who go on to get prophylactic mastectomy is worry and anxiety that may be somewhat out of keeping with their actual risk," says Ann M. Geiger, PhD, at Wake Forest University Baptist Medical Center, the lead researcher of a recent study that looked at quality of life after BPM.

British researchers captured this paranoia in a 1998 study: Women were asked to rate their perceived risk and then underwent genetic counseling. On average, subjects tended to overestimate their risk by 36 percent. Even a year after counseling, more than half of the women continued to misjudge their odds. Lisa, for one, tested negative for genetic mutations, but the results scarcely put her at ease. "I've been told I could still have an undetected mutation within my family," she notes. Plus, the physical and psychological insult of the testing process itself, with its serial scans and biopsies—Mal recalls feeling "chipped away"—can cause women to believe that it's just a matter of time before they receive a positive diagnosis.

Ironically, the flurry of public pink-ribbon campaigns and media attention about the disease that has channeled more than half a billion dollars per year in federal research funds to the cause may have helped foster a culture of fear. "All this attention has come at a cost," says Diana Zuckerman, PhD, president of the National Research Center for Women & Families. "The effort to raise awareness of breast cancer and increase mammography has resulted in women being more afraid of breast

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cancer than they should be and at a younger age than they need to be."

What is a woman's real risk? The National Cancer Institute puts it at one in eight over a lifetime. Of course, the odds increase with age, starting with a roughly one in 1,985 chance during a woman's twenties. That jumps to a one in 229 chance in her thirties, one in 68 in her forties, and so on to her seventies, when she faces one in 24 odds of getting the disease. Several other variables also come into play, including the age at which a woman reached menarche (longer exposure to estrogen increases vulnerability), when she first gave birth (having a child before 30 and breast-feeding can be protective), and the number of first-degree relatives who've had breast cancer—mitigated by factors such as toxic exposure, diet, and exercise. Less than 10 percent of breast cancers spawn from gene mutations such as the BRCA1 and BRCA2, which are found more commonly among Ashkenazi Jews, but these genetic markers put carriers at a seriously high risk of developing the disease (between 36 and 85 percent, according to a recent analysis of existing studies).

Not surprisingly, family history is the single biggest factor that influences a woman's decision to pursue BPM, according to Marlene H. Frost, RN, PhD, lead author of a study published in *Journal of the American Medical Association* in 2000 and assistant professor of oncology at the Mayo Clinic College of Medicine. In fact, it almost seems as if having a close relative who's battled cancer is as traumatic as experiencing the disease itself.

In a 2003 study of first-degree relatives of breast cancer patients, more than half report "intrusive thoughts about breast cancer," a third have experienced "impairments in daily functioning," and 20 percent suffer from sleep disturbance due to anxiety, according to Kelly A. Metcalfe, RN, PhD, assistant professor at the University of Toronto's Faculty of Nursing. Lisa sleeps only four to five hours a night as opposed to seven before cancer worry took over. Her 17-year-old daughter is touring colleges, she says, "and my mind is somewhere else. I should be there—I feel guilty." Some high-risk women who've cared for family members battling the disease may even exhibit symptoms associated with post-traumatic stress disorder.

Perhaps more surprisingly, a study of daughters of breast cancer patients has shown that they have sex less often, and have less satisfying sex, compared with those whose mothers haven't had the disease. "Why should I get attached to my body and start enjoying sex when all of that will be totally destroyed when I get breast cancer like my mother did?" asked one woman in a paper published in *Psychosomatics* in the early '90s. Authors of the study speculated that girls who are teenagers at the time of their mothers' cancer may associate their developing bodies "with illness, body-image trauma, and even death."

Another factor influencing the appeal of BPMs may be advances in surgical options, which have become more "elegant," in the words of one surgeon: more preserving of the anatomy and with less scarring than, say, when Mal's mother went under the knife. Most BPM patients opt for breast reconstruction, which, thanks to new tissue transfer methods, looks and feels more natural than ever (reconstruction patients are exempt from the restrictions on silicone implants in the United States).

But many in the oncology community worry about the ethical implications of performing a BPM when it's not necessary

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(doctors differ on exactly what the risk threshold is, though one who declined to be identified put it at greater than 30 percent). "If someone comes in with a cavity and wants all of his teeth removed, only a bad dentist would remove all the teeth," says William C. Wood, MD, chairman of the department of surgery at Emory University School of Medicine. A woman who insists on BPM against her doctor's advice, he adds, may need psychiatric counseling. "If you rush to do something thinking it will please them, you actually harm them because the anxiety will just go to a new house to settle on," he says.

Besides, a woman's chance of dying from breast cancer has been slowly but steadily dropping for the past decade (it's now one in 33 of all women). Zuckerman sums up the position of doctors who refuse to do the surgery without medical cause: "As long as she's getting regular mammograms, there's no reason why she would ever die from breast cancer even if she were to eventually get it, and no reasonable person would want a prophylactic mastectomy under those conditions."

Define reasonable, others would contend. "If a woman can't make it through [the day] because she's so worried about breast cancer, then why shouldn't we allow her? It's a quality of life issue," Metcalfe counters. She and others point to the almost uniformly positive outcome of the surgery. According to various studies, the vast majority of women—70 to 97 percent—who have chosen BPM are satisfied with the result. According to Frost's research, nearly three quarters of those women report reduced concern about developing breast cancer; almost as many say they'd do it again. Not surprisingly, nearly all the women who underwent BPM were married; most report no negative impact on their sex lives or feelings of femininity. In an odd twist, women who don't get reconstruction often feel more comfortable with their bodies than those who do, says Zuckerman.

"Some people just feel better about the fact that they've faced and made a difficult decision," says Karen Hurley, PhD, an assistant attending psychologist at Memorial Sloan-Kettering Cancer Center, who counsels women who undergo BPM. "They feel empowered that they can face other difficult decisions in their lives."

One poignant footnote: According to Geiger, half of BPM patients remain concerned about breast cancer after their surgeries. "It could be that some women are going to continue to worry about their risk regardless of any steps taken to reduce it," she explains.

Back at the doctor's office, Lisa's latest abnormality is determined to be another cyst, but her radiologist warns that she might need another biopsy because of the "suspicious" discharge. "Honestly, I don't know what [another biopsy] will do to me," Lisa says. "I'm that much closer to reaching a decision—even though I think [my oncologist] is going to try to talk me out of it." (He turned out to be supportive.) "I can't take the stress of worrying, waiting, and testing anymore." But when asked whether she feels any peace of mind since her results came back negative, Lisa hesitates. "Yes," she says. "For now." □